

Development of the Dementia Positive Living Group Pilot at St Nicholas Hospice Care

By Angela Jiggins, MCSP and Gillian Austin, RN

Positive Living Group (PLG) at St Nicholas Hospice, in its current format was started in 2011 but has gone through a variety of changes since then, developing and adapting according to feedback from patients; as well as learning from the increased experience of staff.

It was set up to provide a four week programme equally for patients and their carers to learn about how to manage symptoms and the difficulties illness brings and work towards setting goals and looking at living rather than dying.

Topics of discussion include fatigue, breathlessness, anxiety, sleep, nutrition, advanced care planning, relationships, body image etc. The only topics off limits are religion and politics. (However people are signposted to our chaplaincy service if they have any spiritual needs that can't be met in their local area.)

It has always been a closed group, with no-one allowed to join after week one; open to all who fit the hospice criteria. Attendees have ranged from a newly diagnosed patient with Multiple Sclerosis to a severely unwell patient with lung cancer who dies after week two.

The focus of the morning is education with peer discussion and the afternoon is more open discussions, one to one discussions, art work, and complementary therapy.

There is a lead of each group - an experienced hospice physiotherapist or occupational therapist. They are supported by a family support therapist, where able, and an experienced/trained volunteer.

The feedback from attendees has helped shape the group - the main goals for attending the groups are information gathering; to be able to better support their partner; to be able to talk to others. The evaluation forms are often very enlightening and include comments such as "Someone to talk to who understands". "Sharing information with others".

Having had some patients attend who have dementia, it was realized that being within a mixed group of conditions with varying needs didn't provide the best setting for them and their needs were not specifically enough addressed.

Within our locality we have dementia teams and services who are far better suited to providing specific advice and support, however as a hospice we are specialists in providing advanced care planning, which is important to do as early on as possible with a dementia diagnosis.

On discussion with the local dementia service we developed the dementia PLG. It is still offered as a 4 week programme but is run off site from the hospice and is a joint venture between St Nicholas Hospice Care and West Suffolk Hospital Dementia Care Team. A maximum of six couples are invited to attend. The focus on symptom management is more tailored to the needs of the dementia patient, the advanced care planning section is the same but more focus is put on signposting to local services and support groups within the final week.

Two out of the three pilot dementia PLG groups have been held, with a full complement of attendees and great success. This has led the hospice to look at funding revenues to be able to continue running the group next year, with the aim for three a year, unless numbers dictate an increase or decrease in this number.

Feedback from the last two dementia PLG groups -

"Helped me come to terms with my condition through 1st class professional advice plus good dialogue with other patients and carers"

"Made me realize there can be a positive future when I felt like giving up"

"Enables a freer dialogue with partner re taboo topics"

"I didn't realize people could be so caring"

"I have come out of myself"

"My social highlight of the past 2 months!"

Learning to adapt to a different 'normal'"

For any further information please contact angela.jiggins@stnh.org.uk, gillian.austin@stnh.org.uk or view St Nicholas Hospice website www.stnicholashospice.org.uk